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# Consumer health information partnerships: the health science library and multitype library system

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The University of Illinois Library of the Health Sciences at Rockford (LHS-Rockford) long has honored a commitment to serving the health information needs of the greater Rockford community. Utilization data collected over the past five years indicate that approximately 50% of reference transactions involve persons not affiliated with the university. In early 1994, LHS-Rockford submitted a proposal to the Northern Illinois Library System (NILS), a multitype system spanning twelve counties in northwestern Illinois, asking to serve as a resource library for improving medical and health information services provided by the 138 NILS member libraries. The NILS funded this pilot project as part of an effort to implement a new strategic plan, which encouraged member libraries to form networks to provide reference back-up service. LHS-Rockford acquired InfoTrac's Health Reference Center, a consumer health information database, and set up a dedicated workstation near the information and circulation desk. Referral guidelines were established and the project was promoted among NILS member libraries. Activities were documented in order to track project success in terms of referrals and outcomes. The demonstration project was very successful, and it proves public consumers seeking health information can benefit greatly from this type of cooperative arrangement.

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## INTRODUCTION

The past two decades have witnessed an ever-increasing demand for patient and consumer health information. Historically it has been the responsibility of the medical profession to provide adequate patient education and information; now there is a shift away from authoritarian medical practice to patient participation. A new, health-conscious generation is choosing to take a more active role than did previous generations in matters pertaining to health, particularly in prevention of illness and in living healthy lifestyles. This new generation is demanding and using information once considered the domain of doctors and other health care professionals [1]. In recent years health care professionals themselves have come to realize that their patients no longer are willing to sit back and let the professional make all of the medical decisions. They also have become much more aware that there can be no significant improvement in the overall health of the population unless individuals

begin to take a more active and responsible role in caring for their own health [2].

A still-appropriate excerpt from a 1977 *Science* editorial states: "[A] 'right' to health should be replaced by a moral obligation to preserve one's health. The individual then has the 'right' to expect help with information" [3]. Lack of knowledge creates a barrier to assuming responsibility for one's own health. To become informed, health consumers must have access to up-to-date, accurate, and reliable medical and health information. Unfortunately, most consumers of health information are unfamiliar with medical terminology and many possess only a rudimentary knowledge of their personal condition. They are "not aware of, or prepared to assimilate and extract, information from the large amount of material available on certain topics" [4]. They must have access to specifically trained individuals who can assist them in sorting through and evaluating information.

This task of assisting health consumers with their information needs is increasingly becoming a role of

the health sciences librarian. The public library, with its mission to serve the public, has always maintained a core collection of medical and health materials that can provide answers to general medical and health questions. Today's sophisticated consumers want more than the basics. In addition to general information regarding diagnoses and treatments, they are seeking the most recent research on drug therapies and surgical techniques, and they want to verify credentials of their physicians. Sources for this type of information are at times beyond the scope of public library collections; the health sciences library is a logical place to try next. In addition to housing a wide-ranging collection of clinical materials, the health sciences library generally has more retrieval tools than a public library [5]. Collaboration between the two types of libraries rapidly is becoming a necessity, as well as a reality.

### A RECORD OF COLLABORATION

The literature reveals a number of cases in which consumer health information needs have been met through institutional collaboration. Perhaps most notable were the consumer health information demonstration projects funded in the late 1970s by Library Services and Construction Act (LSCA) Title I grants. Goodchild [6], Fierberg [7], Fecher [8], and Rees [9] each wrote about the Consumer Health Information Program Services (CHIPS) project. One of the first efforts to bring public and health sciences libraries together, CHIPS was established in 1976 to coordinate the efforts of Los Angeles County Harbor General Hospital Regional Medical Library and the county's Carson Regional Public Library to provide health information to a target population of more than two million people.

The Consumer Health Information Network (CHIN) project, described separately by Rees [10], Gartenfeld [11], and Dalton [12] was another attempt to coordinate and improve health information services by bringing together the skills and resources of public and health sciences libraries. The CHIN project was created in 1977 in Cambridge, Massachusetts, by Mount Auburn Hospital and six public libraries in the catchment area of the hospital. More recently, in 1990, Michael et al. [13] described an LSCA Title I consumer health information program established in rural Missouri, where twenty-five public libraries were invited to band together to improve access to medical information. In 1994, Humphries and Kochi [14] described a collaborative effort involving an academic medical library and several public and community-college libraries to provide current health information to residents of Virginia.

These projects paved the way for a variety of consumer health information programs, both collabora-

tive and individual efforts, which have served health consumers throughout this country and beyond.

### PROJECT BACKGROUND

In the spring of 1994 the Northern Illinois Library System (NILS) and the University of Illinois Library of the Health Sciences at Rockford (LHS-Rockford) joined forces to provide up-to-date consumer health information to residents of northwest Illinois. NILS is a multitype library system serving more than 650,000 people and spanning twelve counties in northwest Illinois. The system has 138 members: fifty-five public libraries; fifty-eight school libraries; eight academic libraries; and seventeen special libraries, including seven health sciences libraries. Four of the seven health sciences libraries within NILS are located in Rockford, the largest city in the NILS region. Much of the territory covered by NILS is primarily rural, with many areas designated as medically underserved by the U.S. Department of Health and Human Services.

LHS-Rockford, a regional site of the University of Illinois Library of the Health Sciences at Chicago, serves the information needs of faculty, students, and staff of the University of Illinois College of Medicine at Rockford (UICOM-R). UICOM-R was established in 1971 as part of an expansion of the University of Illinois College of Medicine. Its approach to teaching medical students is community based, and it owns and operates three community health centers in rural northwestern Illinois to help meet health services needs in those medically underserved areas. In 1993 UICOM-R implemented a rural medicine training program and will be graduating its first class in 1997.

In keeping with the mission of the College of Medicine, LHS-Rockford honors a long-standing, informal commitment to serve the broader Rockford community as well as the university community. While emphasizing a clinical and biomedical collection, the library maintains approximately 1,000 consumer-oriented books, which are labelled "Consumer Health Collection" so that they are readily identifiable, and a few journals, which are integrated into the clinical collection. The library also houses a collection of approximately 200 consumer-oriented pamphlets on a variety of subjects. These uncataloged pamphlets are organized by subject in a public display area, and are available to the public at no charge. Unaffiliated patrons may obtain borrowing privileges at LHS-Rockford and, with proper identification, may check out all materials that circulate to the university community.

In recent years LHS-Rockford has experienced a steady increase in the percentage of reference activity attributed to unaffiliated users (see Table 1). These

**Table 1**  
LHS-Rockford: reference activity recorded by user group

|               | 1989-90 | 1990-91 | 1991-92 | 1992-93 | 1993-94 |
|---------------|---------|---------|---------|---------|---------|
| Faculty/Staff | 1,991   | 1,394   | 593     | 590     | 484     |
| Student       | 1,341   | 2,257   | 1,714   | 1,733   | 1,165   |
| Other         | 2,064   | 3,282   | 2,332   | 2,394   | 1,758   |
| Total         | 5,396   | 6,933   | 4,639   | 4,717   | *3,407  |
| % Other       | 38%     | 47%     | 50%     | 51%     | 52%     |

\* The sharp decrease in overall reference activity may be explained by the acquisition of the Health Reference Center database as well as free access for faculty, staff, and students to a host of National Library of Medicine databases via the Internet.

users, including students from surrounding area colleges and community health professionals as well as public consumers of health information, have accounted for approximately 50% of recorded reference transactions for the past several years.

## THE PROJECT

In early 1994 the NILS board approved the appropriation of monies from a reserve fund to support demonstration projects that would help implement a new strategic plan for reference services. One of the goals of this plan was to encourage member libraries to form networks within NILS that could serve as reference backup. An advisory committee was formed to advance this goal. This committee, known as Forging Links for Information Exchange and Reference Service (FLIERS), encouraged NILS members to submit proposals, indicating that preference would be given to projects that would (1) involve clusters or the entire system rather than only a few libraries in a single location, and (2) involve different types of libraries.

Funding for FLIERS pilot projects was intended to be "seed money" for trying out a proposal and assessing its value to NILS reference services. Funding at a reduced level would be considered for a second year. Continuation of funding by project participants was an important consideration in the decision-making process. Participants would be required to record utilization data and furnish reports on monies spent to NILS/FLIERS. Projects would be evaluated twice, after six months and after one year.

Several member libraries proposed projects designed to advance the goals of cooperation and sharing among NILS members in providing reference services. Among these was a proposal submitted by LHS-Rockford. This proposal, "Enhancing Access to Consumer Health Information," called for NILS to con-

sider LHS-Rockford a resource library for improving medical and health-information services for all NILS members.

Project goals were to (1) acquire a microcomputer with a CD-ROM drive and a one-year subscription to Information Access Company's (IAC) Health Reference Center (HRC) database, to set up a workstation that could deliver consumer health information; (2) adopt and publicize guidelines calling for provision of consumer health information at the earliest point of contact; (3) develop a directory, guide, or pathfinder for health-information resources in the NILS region; (4) develop a core list of eight to ten reference titles that a small public library might purchase to answer approximately 50% of its consumer health information questions; and (5) develop referral guidelines and forms for member libraries handling consumer health questions.

The HRC database is updated monthly and provides current information (on a rolling three-year basis) about health-related topics found in more than 150 core health journals, including the *Journal of the American Medical Association* and the *New England Journal of Medicine*. Articles appearing in approximately two-thirds of these journals are presented in full-text format. The database also includes the full text of more than 500 pamphlets published by government agencies and national associations, and five medical reference books—*Mosby's Medical and Nursing Dictionary*, *Columbia University of Physicians and Surgeons Complete Home Medical Guide*, *The People's Book of Medical Tests*, *USP-DI Vol. II Advice for the Patients: Drug Information in Lay Language*, and *Rees' Consumer Health Information Source Book*. Citations or text for health-related articles from more than 2,500 general-interest magazines and newspapers, including the *Los Angeles Times*, *The New York Times*, and the *Wall Street Journal* are also part of this database.

The HRC database was chosen instead of other consumer-oriented health information databases because it contained full-text information, received positive reviews in the literature, and was highly recommended. Previous experience and success with other IAC software products were also considered in choosing this product.

LHS-Rockford agreed to evaluate the project by tracking total database use; number of referrals to LHS-Rockford by NILS member libraries; number of referrals by health professionals; and outcomes, that is, the usefulness of the database in answering consumer health questions. LHS-Rockford staff were also to work with the NILS/FLIERS group in developing referral guidelines and a core list of consumer health reference books. They agreed to make every effort to respond to NILS member requests for consumer health information in a timely manner yet reserved the prerogative of assigning

highest priority to their primary clientele—the faculty, students, and staff of UICOM-R.

## IMPLEMENTATION

In March 1994 the LHS-Rockford project was approved for funding by NILES and received the support of the University of Illinois at Chicago Library administration. A microcomputer with a CD-ROM drive was purchased and a workstation dedicated to HRC was set up near the online public access catalog and the circulation desk at LHS-Rockford.

Referral guidelines for all NILES libraries were established as follows: (1) all consumer health information requests would be considered within the scope of the project, (2) referring libraries would check resources available in their own collections before referring the question to LHS-Rockford, (3) referrals would be submitted via fax or van delivery service directly to LHS-Rockford on a standard NILES Information Request form, and (4) no referral form would be necessary for referrals made in person.

The consumer health project was publicized and promoted widely among NILES member libraries to increase awareness of the new service. LHS-Rockford hosted a meeting of NILES reference librarians to demonstrate HRC and other databases, including MEDLINE, that are available to the public.

One goal of the project was to develop a core list of health information resources that small public libraries might purchase at reasonable cost to answer approximately 50% of their consumer health information questions. LHS-Rockford staff and the NILES/FLIERS committee examined several lists of consumer health information available in publications such as *Library Journal*. In addition, a message was posed on MEDLIB-L, an Internet listserv, asking subscribers to provide their favorite sources for answering consumer health questions. A final list of resources was compiled from the top five choices of members of the FLIERS Consumer Health Information subcommittee and LHS-Rockford Information Services staff, and from the responses of about twenty persons responding to the request on MEDLIB-L. Each title included on the list was chosen by several persons as a favorite resource. This list is provided in the appendix.

Once the system was running, Circulation and Information Services staff at LHS-Rockford were instructed in how to search HRC and address minor problems with the equipment. All library staff were encouraged to direct unaffiliated patrons—particularly public consumers and students—to this resource to begin their search for information. The HRC database was the first resource used for all questions referred on a NILES Information Request form. If a question could not be answered satisfactorily with information found in this database (in the judgment

of the person handling the request), then other resources were consulted. If a list of citations was included with materials sent, then the patron was informed that those references could be obtained through interlibrary loan at a local public library.

## EVALUATION AND RESULTS

During the one-year period of the demonstration project, users were encouraged to complete a brief questionnaire developed by LHS-Rockford staff. This questionnaire was designed to determine patterns of referral and the usefulness of HRC in answering consumer health questions. This questionnaire was placed at the HRC workstation. Given the brevity and objective nature of this form, it was felt that LHS-Rockford reference librarians could complete an evaluation form for each consumer health information question formally referred to them with a NILES form.

Over the course of the project, 353 HRC users (an average of twenty-nine per month) completed an evaluation form. (This number includes evaluations completed by LHS-Rockford staff for NILES referrals.) This number reflects only a small percentage of the total usage of HRC, as evidenced by statistics generated by the system. System-generated statistics were collected on a monthly basis to determine the number of searches conducted and the amount of time logged on the system. These figures were recorded in a log to determine how much HRC was used during the project year. Statistics showed a monthly average of 694 searches conducted on HRC (averaging 256 during summer months and 840 during the academic year). An average of forty-three hours per month (averaging seventeen hours during summer months and fifty-one hours during the academic year) were logged on the system. As expected, December showed a significant drop in usage.

Following project guidelines, utilization data were also recorded to determine referral patterns and outcomes. Responses showed that 131 of the HRC users (37% of the total) who completed an evaluation form were referred to LHS-Rockford by another library. This number included formal referrals from a total of forty-four NILES member libraries which included public, school, and special/hospital libraries. Table 2 shows overall referral patterns. It should be noted that local hospital librarians sometimes come to LHS-Rockford to find consumer health information; their responses regarding the usefulness of HRC are included in these data.

Responses regarding the usefulness of HRC in providing information needed to answer medical and health questions were favorable. A total of 202 (57%) of the respondents who completed an evaluation form indicated that they had found enough information on HRC alone to answer their consumer health ques-

**Table 2**  
Sources of referral to LHS–Rockford (*N* = 353)

| Another library | Association or agency | Health care professional | Self-referral | Other     |
|-----------------|-----------------------|--------------------------|---------------|-----------|
| *131<br>37%     | 19<br>5%              | 45<br>13%                | 100<br>29%    | 56<br>16% |

\* This number includes formal referrals from a total of forty-four (32%) NILES member libraries, including public, school, and special or hospital libraries.

tions; 88 (25%) were able to answer their questions using materials found on HRC in combination with other resources, both consumer and clinical, from the LHS–Rockford collection. Fifty-eight (16%) respondents reported that they were unable to find the necessary information on HRC but were able to obtain information from other resources in the library, generally textbooks or journals from the clinical collection. Only six (2%) of those completing an evaluation form indicated that their questions were not answered. These patrons were referred to other appropriate sources.

A majority of the persons using LHS–Rockford to find consumer health information were enthusiastic and positive in their comments about HRC. Typical responses were "great service," "quick and easy to use," "saved a lot of time in doing research," and "wonderful system." Respondents were impressed with how user friendly the system was, noting that someone with any level of computer literacy could sit down and do a successful search. They were also pleasantly surprised to discover that the full texts of much of the information found on the database could be printed.

Of particular importance to a great many users was the physical location of this database in a health sciences library. Housing HRC in the health sciences library provided users with access not only to resources found in this database but also to a wide range of other consumer and clinical resources and the requisite tools to search them. That many HRC database users went on to seek additional sources of information may support Rees' observation that "[e]vidence indicates electronic availability [of information] tends to stimulate rather than supplant the demand for print equivalents" [15].

## DISCUSSION

Health Reference Center helped to diminish some of the traditional barriers to providing consumer health information. Because the system requires little or no formal instruction or intervention by library staff, it affords confidentiality to patrons who otherwise might

feel uncomfortable consulting a librarian concerning problems of a personal nature. In addition, unlike some of the more clinical databases, such as MEDLINE, HRC provides consumers with information geared to the layperson. Perhaps of greatest value, this resource gave library staff more time for other tasks. Prior to its implementation, library staff spent a significant amount of time interviewing unaffiliated students and consumers, and helping them to search more clinical, and sometimes less appropriate, databases in order to obtain current medical information.

The range of information found in HRC proved beneficial to all types and levels of users. For the health consumer it often served to bridge the gap between basic health information and the often more complex information found in LHS–Rockford's clinical collection. One surprising finding was that medical and nursing students, physicians, and residents from the on-site Office of Family Practice, the primary clientele of LHS–Rockford, often used HRC to do their own quick searches to find information for patients.

Health Reference Center on CD-ROM presented few problems. The system was easy to set up and maintain, and library staff spent a minimal amount of time solving technical problems during the project year. One minor unanticipated problem was the excessive length of time—sometimes longer than an hour—a single patron might use the database. To remedy this situation patrons were encouraged to limit their searches to twenty minutes if others were waiting. Information Services staff were encouraged to use HRC early in the morning, generally a slow period, to fill NILES information requests. Some patrons also tended to print out large quantities of information. Project staff decided not to place limits on the number of citations a patron could print; however, the system does support options regarding the quantity of materials users may print.

## CONCLUSIONS

For the most part, the primary goals set forth in the project plan were met. A CD-ROM workstation was established at University of Illinois Library of the Health Sciences at Rockford, permitting the library to serve as a resource for disseminating health information to patrons of public, school, and special libraries in the Northern Illinois Library System. The project was publicized and promoted among all NILES members and referral guidelines were developed that enabled citizens in the NILES geographic area to find answers to their consumer health questions in a timely manner. A core list of consumer health reference books was compiled and made available to all NILES members to assist them in establishing, at reasonable cost, a small collection that could be used to answer

approximately 50% of consumer health information questions. The final goal, to develop a directory, guide, or pathfinder for health information resources in the NILS region, was discussed and eventually eliminated, because all parties involved felt that it would not advance the primary goal of providing accurate, up-to-date consumer health information.

The project demonstrated the benefits that may accrue to any type of library or library system and its patrons through the acquisition of Health Reference Center, or a similar consumer health database, to establish or supplement an existing consumer health collection. This is particularly true for sparsely populated, rural areas—such as the one covered by NILS—that have access to few consumer health information resources. High initial expenses may lead libraries to collaborate in order to distribute the cost among several parties. Once in place, however, the system saves resources by enabling broad dissemination of consumer health information to consumer constituents at minimal personnel cost.

#### FINAL NOTE

A similar demonstration project at the University of Illinois Library of the Health Sciences at Chicago (LHS-Chicago) received strong support from a variety of users. Because positive responses to the HRC database were noted at both LHS-Rockford and LHS-Chicago, the latter applied for and received an LSCA Title III grant. Funds from that grant made possible the establishment of a networked version of Health Reference Center to serve eight sites—three public libraries, one hospital clinic, and the four libraries of the health sciences located in Chicago, Urbana, Peoria, and Rockford. Because the LHS-Rockford demonstration project received favorable feedback, NILS agreed to provide funding for an additional one-year subscription to the HRC database to be incorporated as part of the Title III grant. One hopes that the project will provide a prototype for statewide cooperation among academic health sciences libraries and public libraries in providing consumer health information services.

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#### APPENDIX

##### Core list for small libraries

- American Medical Association Encyclopedia of Medicine. Random House, 1989. (\$45)
- Current Medical Diagnosis & Treatment. 33d ed. Appleton & Lange, 1994. (\$40 paper) (annual)
- Magalini, Sergio I. Dictionary of Medical Syndromes, 3d ed. Lippincott, 1990. (\$40)
- Mayo Clinic Family Healthbook. Morrow, 1990. (\$40)
- Merck Manual of Diagnosis & Therapy. 16th ed. Merck, (\$26)
- Professional Guide to Diseases. 5th ed. Springhouse, 1995. (\$33)

and one of the following:

- The Essential Guide to Prescription Drugs. Harper Perennial, 1994. (\$35; \$17 paper)
- The Complete Drug Reference. 1995 ed. United States Pharmacopeia, Consumer Reports Books, 1994. (\$40) (annual)
- PDR Family Guide to Prescription Drugs. 2d ed. Medical Economics Data, 1994. (\$25 paper)